

The Hormone Foundation's Patient Guide to Growth Hormone Deficiency in Adults

Why were the guidelines written?

This patient guide is based on clinical guidelines that were written to help physicians who are evaluating and treating patients with growth hormone deficiency (GHD). It summarizes information about the best way to diagnose GHD in adults, how physicians will begin care and follow-up with patients who have a diagnosis of GHD, and the potential benefits of growth hormone (GH) treatment. This guide also provides information for patients with GHD to help them improve the outcome of their treatment.

The guidelines do not apply to people who want to take GH to prevent aging or to improve their strength or athletic performance. Claims about using GH to slow down the aging process or help build muscle in athletes have not been shown to be true and such use may cause harm.

How were the guidelines developed?

The clinical guidelines were developed after an extensive review of the best clinical studies about GHD and treatment with GH. An expert panel of The Endocrine Society examined evidence from studies that had been published in "peer-reviewed" medical journals (that is, the studies were carefully evaluated by the journal's scientists and editors). The panel rated the quality of the studies and gave the most weight to studies that were randomized and placebo controlled. This means that the people in the study were assigned into groups at random. One group took the study drug and the other took the placebo (an injection that did not contain the GH). This allows physicians to learn whether the GH injection is more effective than no treatment at all.

The panel developed "Recommendations" based on these types of studies or "Suggestions" based on studies that were less rigorously designed or carried out. Once the panel reached an agreement about their "recommendations" and "suggestions," the guideline was reviewed and approved by several committees and, finally, by the general membership of The Endocrine Society. No funding for the guidelines came from any pharmaceutical company.

What are the causes of GHD?

Adults with GHD fall into two categories:

- 1) Those whose GHD developed during childhood
- 2) Those whose GHD developed after reaching adulthood

The actual causes of GHD include inherited causes that are present at birth. These might involve problems of GH production in the pituitary gland and other disorders of pituitary development (e.g., defects in the gene responsible for producing GH). Other causes that can take place at any age involve damage to the pituitary, which may be from tumors, surgery, irradiation and other types of trauma. Rarely, GHD is of unknown origin (idiopathic GHD).



Therapeutic goals of GH therapy

- Build muscle mass
- Lower fat levels
- Build stronger, healthier bones
- Improve heart function
- Increase energy

What are the goals of GH therapy?

The panel recommended that if you had childhood GHD with structural lesions (i.e., tumor or surgery in the area of the pituitary) and other pituitary hormone deficiencies, or if you have proven genetic causes, a low IGF-1 level at least one month off of GH therapy shows that you have GHD and, therefore, you won't need further testing. (IGF-1 is Insulin-like Growth Factor-1 and is regulated by GH from the pituitary gland to cause growth.) On the other hand, if you had childhood GHD without structural lesions or other pituitary hormone deficiencies the panel recommended that you should be retested as an adult. The panel also recommended that as little time as possible go by between the end of your childhood treatment and the testing.



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Diagnosing GH deficiency in adults can be difficult. It requires one or more tests to determine if the deficiency is present and if it is severe enough to require treatment. The panel found that the *insulin tolerance test* and the *GHRH-arginine test* are the most specific and sensitive tests for diagnosing GHD in adults. Doctors need to work with each individual to determine the most appropriate tests and to determine the best treatment.

The primary goal when prescribing growth hormone injections is always to replace the normal amount of growth hormone the individual would have if he or she did not have a deficiency of the hormone. Taking too much growth hormone over a prolonged period of time can be harmful. Your doctor can best explain all the risks and benefits of GH replacement and other treatments that you may need.



To achieve your treatment goals, take your recommended medication, keep regular appointments with your doctor, and adopt a healthy lifestyle that includes regular exercise and good nutrition.

The panel found evidence that treatment of adult GHD achieved the following therapeutic goals:

- **Building muscle mass and decreasing fat levels in your body.**
- **Building stronger, healthier bones.** GH stimulates both bone formation and bone resorption (the breakdown process of old bone, essential to health). Patients should have a DXA bone scan to measure bone mineral density (BMD) before treatment. If it is abnormal, a BMD test should be done about every two years after starting GH treatment
- **Improving heart function.** Replacing GH sometimes helps by improving heart functioning and reducing the markers of inflammation, which indicate risk for heart and blood vessel damage. GH also improves metabolism of lipoproteins (fat molecules) and decreases the amount of bad cholesterol (low-density lipoprotein) and total cholesterol as seen in blood tests.
- **Increased energy.** Energy, vitality, and exercise capacity increase in some people who are treated with GH. The degree of improvement depends on the individual's status before treatment. Not everyone will see an improvement.

How will your doctor help you get to your treatment goals?

Your endocrinologist, a specialist in growth hormone treatment, will carefully evaluate you and determine whether

or not you need GH and, if you do, what is the right dose of GH for you. The panel recommended that GH should not be given if you have a diagnosis of cancer. In addition, they suggested that for those patients who also have diabetes mellitus that their diabetes medications may need to be adjusted because GH treatment can raise blood sugar.

The panel recommended that the dose of GH should be individualized. Your weight, gender, age, and other medications you might be taking should be taken into account. The dose of GH may be adjusted over time. Doctors usually start by giving a low amount of GH. This may be increased if your blood tests show you could benefit from more GH to reach your health goals. Doctors adjust GH doses based on how you are responding and on any side effects you may have.

While GH is always prescribed on a case-by-case basis that looks at the entire individual, most doctors who provide GH treatment want to see their patient for a check-up every one to two months to check for progress and any side effects. Once the right dose is established and tests show that the GH is benefiting you as much as possible, you may only need to follow up every six months.

Your doctor will also take into account any other medications you need and make sure that all of your medications are working together as well as possible. If you are taking more than one medication, make sure your endocrinologist and primary care physician know about all of the medications you take.

If you feel different or worse after you begin a drug, call your doctor. Your new symptoms may be a side effect of the drug or an interaction from taking more than one drug.

What can you do to help your treatment process?

Treatment for GHD usually needs to be continued for many years and possibly for a lifetime. One of the most important things you can do as a patient is to keep taking your recommended dose of GH and medications you might be taking to treat other conditions. Another is to report any side effects you may have to your doctor. You also will improve your health by having a healthy lifestyle that includes regular exercise, good nutrition, limited alcohol consumption, not smoking, and weight loss if you are overweight.

You and your doctor should be partners in your care. Keep regular appointments with your endocrinologist, ask questions and participate in your care to ensure the success of your GH treatment. And remember that if you have not been diagnosed with GHD, using GH can be dangerous to your health.

EDITORS

Mark Molitch, MD
Robert Vigersky, MD

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